

AMENDED IN ASSEMBLY AUGUST 5, 2004

AMENDED IN ASSEMBLY JUNE 21, 2004

AMENDED IN ASSEMBLY JUNE 8, 2004

AMENDED IN ASSEMBLY MAY 3, 2004

AMENDED IN SENATE JANUARY 6, 2004

AMENDED IN SENATE MARCH 24, 2003

SENATE BILL

No. 142

Introduced by Senator Alpert

(Principal coauthor: Assembly Member Cohn)

(Coauthors: Senators Kuehl, McPherson, and Speier)

(Coauthors: Assembly Members Lieber, Maddox, Maldonado,
Plescia, Richman, and Spitzer)

February 6, 2003

~~An act to amend Sections 124977, 124980, 125000, and 125001 of~~
An act to add Section 124978 to the Health and Safety Code, relating
to genetic testing.

LEGISLATIVE COUNSEL'S DIGEST

SB 142, as amended, Alpert. Genetic testing.

Existing law requires the State Department of Health Services to charge a fee for newborn screening and followup services, and requires the amount of the fee to be established pursuant to regulation and periodically adjusted by the director.

This bill would require the department to convene a working group to evaluate newborn and prenatal screening billing procedures and to report its recommendations to the department by March 1, 2005. The

bill would require any written recommendations of the working group to be provided to the appropriate policy and fiscal committees of the Legislature.

~~(1) The Hereditary Disorders Act, among other provisions, declares the intent of the Legislature that the state's hereditary disorders program activities are to be fully supported by fees collected for services provided by the program, unless otherwise provided. Existing law requires the department to charge a fee to all payers for any tests or activities performed pursuant to provisions relating to genetic disorder prevention services, including the Hereditary Disorders Act. Existing law requires that any fee charged for screening and followup services provided to Medi-Cal eligible persons, health care service plan enrollees, or persons covered by disability insurance policies are to be paid directly to the Genetic Disease Testing Fund, a continuously appropriated fund, to be used for purposes of the Hereditary Disorders Act, subject to the terms and conditions of the applicable health care service plan or insurance coverage. Under existing law, all moneys collected by the department pursuant to the act must be deposited into the fund. In addition, on and after July 1, 2002, the State Department of Health Services is required to charge a fee for newborn screening and followup services, and requires the amount of the fee to be established pursuant to regulation and periodically adjusted by the director.~~

~~This bill would make legislative findings and declarations with respect to the need for expanded genetic testing of newborns in California.~~

~~This bill would delete the requirement that the director establish and adjust the newborn screening fee. The bill would require the department to convene a working group, with specified membership, to evaluate newborn and prenatal screening and billing procedures, and to report its recommendations to the department by March 1, 2005.~~

~~(2) Existing law requires the Director of Health Services to establish necessary regulations and standards for hereditary disorders programs, in order to promote and protect the public health and safety. Existing law requires these standards to implement designated principles, including provisions for compensatory and civil damages for an individual whose confidentiality has been breached as a result of a violation of the Hereditary Disorders Act, as well as an award of attorney's fees and litigation costs.~~

~~This bill would revise the above provisions and would additionally provide for imprisonment, a fine, or both, for the knowing breach of~~



confidentiality of an individual tested under the act. By creating a new crime, the bill would impose a state-mandated local program.

(3) Existing law requires the State Department of Health Services to establish a genetic disease unit to coordinate all departmental programs in the area of genetic disease. Existing law requires the genetic disease unit to evaluate and prepare recommendations on the implementation of tests for the detection of certain hereditary and congenital diseases.

This bill would add biotinidase disorders of fatty and organic acid metabolism to the diseases for which the genetic disease unit is required to evaluate and prepare recommendations.

This bill would require the department to expand statewide screening of newborns to include tandem mass spectrometry screening for fatty acid oxidation, amino acid, and organic acid disorders and congenital adrenal hyperplasia, and to provide information with respect to these disorders and testing resources to all women receiving prenatal care and admitted to a hospital for delivery. If the department is unable to provide statewide screening for these disorders by July 1, 2005, the bill would require the department to temporarily obtain statewide screening for these disorders from one or more laboratories, through a competitive bid process. The bill would also enact related reporting requirements.

(4) The California Constitution requires the state to reimburse local agencies and school districts for certain costs mandated by the state. Statutory provisions establish procedures for making that reimbursement.

This bill would provide that no reimbursement is required by this act for a specified reason.

Vote: majority. Appropriation: no. Fiscal committee: yes. State-mandated local program: yes *no*.

The people of the State of California do enact as follows:

1 ~~SECTION 1. The Legislature finds and declares all of the~~
2 ~~SECTION 1. Section 124978 is added to the Health and Safety~~
3 ~~Code, to read:~~
4 ~~124978. (a) The director shall convene, in the most~~
5 ~~cost-efficient manner and using existing resources, a working~~
6 ~~group comprised of health insurance, health care service plan,~~
7 ~~hospital, consumer, and department representatives to evaluate~~
8 ~~newborn and prenatal screening fee billing procedures, and to~~
9 ~~recommend to the department ways to improve these procedures in~~

1 *order to improve efficiencies and enhance revenue collections for*
2 *the department and hospitals. In performing its duties, the working*
3 *group may consider models in other states. The working group*
4 *shall make its recommendations by March 1, 2005.*

5 *(b) Any written recommendations of the working group shall be*
6 *provided to the appropriate policy and fiscal committees of the*
7 *Legislature.*

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10 **All matter omitted in this version of the**
11 **bill appears in the bill as amended in the**
12 **Assembly, June 21, 2004. (JR 11)**
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14

